Autism and Seizures-Silently Seizing: Common, Unrecognized, and Frequently Missed Seizures, and Their Potentially Damaging Impact on Individuals With Autism Spectrum Disorders

Tricia Polchowski is a veteran special education teacher and Board Certified Behavior Analyst. She has worked for 20 years in the field of special education, specializing in children with autism and co-morbid conditions. Her personal experience with her teen son who has autism and was recently diagnosed with a seizure disorder puts her on the front lines of this emerging condition. She works with families who are trying to understand silent seizures and to access information to present to medical professionals. She is frequent presenter in the national and international arenas in the areas of autism spectrum disorders, applied behavior analysis, and seizure disorders.

Minta: Hi, everybody, and welcome back. We're at the 4th Annual Conference for Moms Fighting Autism. We have with us today Patricia Polchowski. She's an autism seizure specialist. Welcome to the show Patricia. I'm so glad that you came to speak to our audience via the webinar. Thank you for joining us. Without further ado, Patricia Polchowski.

Patricia: Thank you. It's a pleasure to be here. As many as 50 percent of children who are diagnosed from autism may also suffer from silent, difficult to recognize seizures. These seizures are often easily treated with medication. My partner is Caren Haines, and she's the author of a groundbreaking book recently released entitled "Silently Seizing: Common, Unrecognized and Frequently Missed Seizures and Their Potentially Damaging Impact on Individuals With Autism." I'm going to reference a lot of Caren's work that she's pulled together through this presentation. Through many years of research what Caren discovered was essentially this information could improve the outcomes for the 1 in 50 children who are currently being diagnosed with autism in the United States.

It's imperative for parents and professionals to know that the behaviors that are used to diagnose autism, such as language
outbursts, can also be a form of partial epilepsy which is treatable. These partial seizures are impossible to see with the naked eye and are often missed by the standard technology used, which would be an EEG. An EEG typically only picks up the top centimeter of brain activity. These type of seizures are often very, very deep in the brain.

This problem is really having tragic consequences for these children and their families because language and behavior originate inside the brain, yet most children are diagnosed just using the behavioral observations. Once the diagnosis of autism is made, very few children receive any further evaluation into any other neurological, genetic, or metabolic conditions associated with autism. In a sense, we put the autism in a box and put the lid on it. Every time our child does something that doesn't fit the norm, we throw it in that box and say it's the autism. But, who in their right mind would trust this type of an assessment? Many of us do.

Traditionally when children finally receive their diagnosis of autism, it's looked at as the end of a quest for answers. We know what we're doing. Instead, it should really be the beginning of your quest. These seizures can be easily treated and once they are, the symptoms that led to them being diagnosed with autism in the first place can be greatly improved, and in some children have disappeared altogether. It's imperative that these silent seizures be recognized and treated as soon as possible to preserve the functioning of our children's developing brains.

I'm going to share a little bit about my own journey with my own son, John. My son John followed a typical path in his early development. He made eye contact. He developed language, was interacting. As he approached his one year birthday, a lot of the words he had such as mom, dad, cookie, started showing up less and less. Instead of language flowing out of them, it appeared that the language was flowing away from him.

He also started to have behaviors that included staring spells, and temper tantrums that really didn't seem to connect to
anything that was going on around him. It left us scratching our heads a lot. During the staring spells, which lasted a few seconds, nothing that anyone said could bring him back to us. We contacted his pediatrician for guidance and he suggested we look at other professionals to figure out what else might be going on with our son.

Our first stop was an audiologist. We took John to the audiologist. However he was having a behavioral difficult day, they weren't able to complete the test. But based on what they saw they said, "His hearing is fine. That is not the problem. That's not what we're looking at."

We moved on to the next specialist, which was a speech pathologist. We went to see the speech pathologist who spent quite a bit of time with us. She walked us out to the waiting room and looked at me and said, "Mrs. Polchowski, your son is autistic. You need to call early intervention and get him help." That was it. It was just dropped on us like a bomb. We stood there not quite sure what to do next, where to go, or who we should even talk to at this point.

We moved on to a developmental pediatrician who gave us the diagnosis on the autism spectrum. The recommendation was that we needed to start speech and occupational therapy, and physical therapy, and all these treatments. During this time John was having staring spells, but nothing was happening consistent enough for the doctors to want to investigate it further. We were just told he's visually stimming, he's just not paying attention, it's the autism. He also started to have more and more behavioral tantrums, which really made school and therapy difficult. Again, it was attributed to, "Well, kids with autism, they have these behaviors, they have these tantrums." No one thought to look any further, and we, of course, followed the experts.

Overall, as a society, we place blind faith and complete trust in the professionals who we are always taught know more than we do. The doctors know more than we do. We should follow what they say. At that time we were told that our son would never speak,
play, or make friends. We just had to start to grieve what he wouldn't be, and move on. There was no looking to see what else was wrong. It was, "It's autism. Move on."

As he became older, he continued to have tantrum behaviors, and lots of visual stimming off to the sides. But nothing any of his therapists or specialists did could reduce these behaviors. A few years ago I started to read a little bit about temporal lobe epilepsy and discovered that my son had almost every symptom. I also read about how frequently temporal lobe epilepsy is misdiagnosed in many people, even people with typical development. I was able to find some information, which led me to my partner now, Caren Haines. After talking with her and really going through the information on the brain and the symptoms, it became very, very clear that he had a seizure disorder all along.

As it progressed, the manifestation of these seizures went well beyond staring spells. The more severe seizures that he had produced vicious rage, and undirected violence that really destroyed many of his chances to even be in a school. He had severely injured staff at his school. He had injured myself. He was labeled as a dangerous child, and we were asked to keep him home from school for a few months until we had him under control.

According to the experts reoccurring seizures contribute to nerve cell injury and death in the developing brain. These seizures have been associated with also having a decline in cognitive function, behavioral challenges, and language regression, the exact things that we also look at with autism. Researchers have noted that seizures alter the brain's complex circuitry. When seizures begin early in life, and are untreated, permanent behavioral abnormalities result. Dr. Richard Restak, a clinical professor of neurology at George Washington University, and an esteemed author of many articles on the brain wrote an article called, "Complex Partial Seizures Present Diagnostic Challenge" where he talks about that seizures begin to come under control when you have anti-seizure medication on board and a deterioration in the neural psychiatric status is often seen.
A schizophrenic-like epileptic psychosis often emerges as the anti-convulsives are normalizing and improving the seizures within the brain. It's important to realize that there are two different problems that needed to be treated separately for children to experience remission and have the seizures really come under control. It's also interesting to note that these untreated seizures can produce a schizophrenic psychosis. This association can shed some light on why many, many years ago autism was actually referred to as "childhood schizophrenia." But the good news is that it's never too late for intervention because at whatever point intervention is applied, the brain, a miraculous organ, can heal itself by creating new pathways. This process is called "plasticity of the brain."

It's important to remember that these seizures are sub-clinical. They don't show up on EEGs. They can produce psychiatric symptoms. This often leads doctors to come to the wrong conclusion. When you receive a diagnosis of autism, it's important to ask the physician for a comprehensive diagnostic evaluation because there are many genetic disorders which are very similar to autism, and those need to be identified. Many mitochondrial disorders, inborn errors of metabolism, and overall genetic disorders also can look just like autism. Many of these disorders are characterized by specific intolerances that need to be discovered so things can be avoided in the child's life. If seizures are present, identifying and treating them will markedly improve the level of functioning in our children. Sometimes that improvement is dramatic.

So often we rely on an inexact science to tell us what is wrong with our children, but we don't question that science. This can sometimes lead to the erroneous assumption we all make as to why a child is lashing out, why they're screaming, why they're violent. The truth is we don't know the answer. We don't know why they're doing that. Often our children can't answer the question of what is wrong. However, often when children are diagnosed with autism, everything they do is labeled because of their autism. No one really looks further to find the cause of why our kids are doing what they're doing. Observing and charting behavioral data, and trying to figure out the origin of all these behaviors is really the cornerstone of getting your child help. As part of behavioral analysis, it's essential to determine when the behavior is random, is an internal event, or
is there something in the environment because they're feeling frustrated, or they can't have access to something. Figuring out the difference in those type of behaviors is really critical to unlocking the challenge of having seizures.

Sub-clinical silent seizures are difficult to diagnose because many of us have been taught that the odd behaviors and language delays are just autism. We haven't been given the opportunity to think that maybe it's something else. The origin of behavior is not recognized as a seizure disorder. Tragically, many children descend needlessly into an entirely treatable condition. These silent seizures are hard to detect in part because they initially cause changes that are subtle. On top of that, as I mentioned, an EEG is often used, and that often fails to catch these seizures. Currently the diagnosis remains clinical, that is based on the behaviors that someone is exhibiting, and the patterns in which they occur. One thing that should be noted is that when seizures start to happen, they often present the same way each time. You will start to see a pattern develop.

How many of us have the tools that we need to dissect the behavior of our children with autism? The experts always tell us this is just the way they are and we are supposed to accept it. We grieve our loss, go on with our lives, accepting without question that our children will bang their heads for no reason, walk on their toes, cover their ears, stare into space, episodically scream, self injure themselves, and show aggression towards others. Many of us believe that all of these abnormal behavior are just autism, a disorder for which no existing remedy really will significantly alter the course. This is not so.

Seizures can be responsible for this abnormal behavior that is often misdiagnosed as autism. Autism merely describes a set of symptoms. There's another disorder causing this set of symptoms, and that fact is glossed over. The good news is that once seizures are identified and treated, a person can function at a much higher level. Some children are even recovering. Additionally, if a genetic disorder is present, once the exact disorder is identified, then treatment can begin that is specifically targeted at that disorder.
The anti-psychotic drugs are often used to treat the behavioral components seen in children with autism. Many of these medications actually lower the seizure threshold, which makes seizures more likely to occur. Sometimes this can lead to a worsening of behaviors and just add confusion to the clinical picture you're trying to put together about their neurological function. These medications should only be used when they're necessary. It's essential to parse out the issues in particular that the child has so you can really understand and guide the treatment plan that's in place. Both seizures and psychosis can produce hallucinations, delusions, and aggressive behavior. Treating with one medication at a time is really important in keeping data on the changes that you see so that you can really clarify the clinical picture is important. My son was on Risperdal for many, many years to manage his behaviors. But as the seizure picture became clearer and clearer, his doctors have been able to reduce the behavioral medications that he has been on to almost nothing at this point. The seizures are being well-controlled by seizure medication. This exploration into seizures and treating it with an anti-seizure medication has really brought both his seizures and his behaviors under control, which was tremendous for him.

Often during a seizures a person loses contact with their environment so profoundly, and they can't control their behavior caused by the seizure, or how their body is responding to it. If the seizure is affecting a small part of the brain, awareness of the seizure may remain intact even though the person can't stop it. That is called a simple partial seizure. When the seizure starts to affect a larger part of the brain and then spreads, it's called a complex partial seizure. A person experiencing this type of seizure cannot control the behavior that's produced. They don't recall what happened during the seizure. Some people will act in a bizarre manner. They may start to scream, fumble with their clothes, start to mumble gibberish, take their clothes off, become aggressive, really random type of behaviors. After my son would have a seizure, he would often lay down and hold his head and cry, and look at me with tears, saying, "What's wrong? Am I okay now?" Just holding his head. It was so heartbreaking to see him begging me to help him and I was powerless. I didn't know what to do.
When you look at the possible signs of a seizure, separate it out from autism behaviors just for a second. I'm going to read a list, some of them are on a slide, and there's some additional ones. Déjà vu, having visions from the past, visual hallucinations, auditory hallucinations, racing thoughts, odd feelings in their stomach, tingling feelings, fear, panic, anxiety, dizziness, staring out, loss of vision, difficulty talking, or just not making sense when you're talking, stomping your feet, waving your hands, your eyes fluttering or rolling off to the side, clenching teeth, chewing the inside of your mouth, lip smacking, screaming, falling down, incontinence, headaches, fatigue, making clicking sounds, and aggression. Any of these symptoms can present alone or in combination. Again, once you start to see these, they will occur in a similar pattern each time the child seizes, or has a seizure event.

Post-seizure, the event surrounding a seizures are unlike any other behavior you're going to see. Sometimes it's so mild that we look and just say, "They spaced out. They checked out for a few minutes. They're staring out the window. They're daydreaming." After a seizure, there's often a short period of confusion that can last a few minutes, or longer. The person may ask you, "What happened?" Such as my son, "What happened? What's wrong?" Then, they may seem very confused and disoriented. The seizure can often then be followed by a sudden attack of fatigue and falling into a deep sleep. After a person comes to, they may feel shame and embarrassment, depression, and sadness. They may look around and see that furniture has been tipped over, or someone is crying because they've been hurt. As with many misunderstood conditions, depression can be really profound in people who are having seizures. That needs to always be kept in mind as well because that piece may also need to be treated.

Doctors who are specializing in treating behavioral disorders tend to have little or no familiarity with seizures, other than a grand mal seizures. That's what I have found most people have as a frame of reference, a grand mal seizures. There's this ongoing tendency to attribute all behaviors that occur to just the autism as a neurological impairment without really looking to dissect the origins. On the other hand, you've got neurologists who are familiar with epilepsy but don't really have the understanding of the behavioral symptoms of autism and
the intellectual impairment. You've got two different specialists, but one doesn't really fully understand the other's expertise.

What ends up happening is common sense needs to be applied. It's illogical to believe that somebody would just turn on a dime and have a severe tantrum with severe maladaptive behaviors for no reason because every behavior happens for a reason. If we are upset, there's a reason. If a child has a tantrum out of the blue, and it is not because they are frustrated or wanting something, we have to ask ourselves, "What is the point of this behavior?" The point we often come to with seizures is, "There is no point," because the behavior is not within their control.

If a person has a brain disorder, we need to look at their brain. Seizures and autism reflect a tremendous misunderstanding which results when medical issues in a misunderstood disorder fall squarely at the intersection between neurology and psychiatry. This intersection can be an occasion where experts meet to solve these problems, or it puts a family in no man's land without not being sure what direction to turn. Often we seem to be in the latter.

As concerned parents, we must ask relevant questions and trust our instincts and our own observations. If you believe your child is having silent seizures, and a psychiatrist doesn't agree, you need to explore this with a neurologist, maybe several neurologists. Treatment must be aimed at seizure control with anti-convulsive medications, and then attending to the co-morbid conditions, or conditions that are occurring together, need to be addressed.

I have to empathize that the definitive diagnosis is difficult and complicated because the characteristics of partial epilepsy are so often mistaken for the behavioral abnormality of autism. It is often the seizures that are causing the odd behavior and the language deficits. What's really important to note, and is the crux of Caren's book, is that these seizures and the associated psychosis can be successfully treated, which preserves the function of the developing brain. The brain can
start to heal itself. The loss of language can be attributed to clinical or sub-clinical seizures which originate in the part of the brain that's responsible for language, the temporal lobe. It's critical these seizures be recognized and treated as early as possible.

Our miracle of healing. Once my son's seizures were diagnosed and he was on the correct anti-convulsive medications, he started to regain the skills that he had lost over the years that he was having his seizures. His ability to read, to write, to interact socially, to problem solve slowly started to return. Those autistic behaviors that the doctors called, the staring, the tantrums, and the violent behavior have stopped. This wasn't an overnight fix. Over the last year, we have seen a whole new person emerge, but it's taken us a year to get there. My son still has language challenges and social challenges, but he's connected to us. He's back with us. We're seeing him achieve things we never thought possible. That's our miracle of healing.

My personal experience suggests that when it comes to accurate diagnosis of underlying conditions associated with autism, the earlier is far better than later, but it is never, ever too late to unlock all that your child is able to do. For those who are silently seizing and are treated early with anti-seizure medications, I can share the endorsement of many renowned physicians in the field of autism that many of these children begin to show incredible gains in expressive language, comprehension, and many are starting to speak and to learn. In some cases, IQ points are even rising measurably. These children can become indistinguishable from their same-age peers, attend regular school classes. I also feel that any gain, any step we take forward, is a valuable step forward for our children.

Dr. Fernando Miranda is a brilliant neurologist who founded the Bright Minds Institute in California and works with children who have autism. Dr. Miranda has shared that many of the patients who come to him with a diagnosis of autism are actually experiencing silent partial seizures. Many of Dr. Miranda's patients are getting the correct diagnosis using what he has
called a "deep EEG" which shows these hidden seizures. This newer technology uses many more leads and is more able to locate the deep electrical discharges, whereas the traditional EEG is more on the surface. Hopefully someday this improved technology will be available to all children who are receiving the diagnosis of autism.

Recently Dr. Miranda was interviewed by Claire Shipman from ABC News. I will give you the web site, too, to watch this clip. He talks about how treating seizures with medication aimed at seizure control has produced an astounding result. His web site is www.brightmindsinstitute.com. If you go to that, you'll be able to see his interview.

For those children who have a genetic syndrome that includes seizures, and many of them do, treating that seizure component, again, has led to dramatic improvements in their lives. We are so fortunate to live in a time where we're finally getting this information out in the open. I'm so happy to be able to share this with many of you.

So, you go to the doctor and you say, "I think my child is having seizures." The doctor looks at you and says, "Nothing showed up on EEG," and is not convinced that your child has seizures. In our case we were told that's how autistic children behave. He's handicapped, you need to accept that. Unless he drops and has a seizure on the floor of my office, I'm not going to prescribe any medications. What do you do?

I'm going to share with you a process that I created to help you start to gather data based on what you see. Then you can share this information with your child's doctor. A doctor is more likely to listen to you if you can hand them black and white data versus "I just have that funny feeling something's wrong." A lot of people get scared when you start to talk about data and numbers. But I'll show you it's very easy to work with.

Let me take a step back for a second. There's four reasons people engage in behavior. The first is because they want to get someone's attention. The second is because we want something, we
want the cookie, we want the glass of juice, we want to play outside. The third is because we want to get out of doing something. We're being asked to do something and we want to avoid it at all costs. The last is doing something because it just feels good to us. All behaviors are tied to these four functions.

The clue is if you can't tie a behavior to these functions, this gives you some very important reasons behind a behavior. If the reasons for behavior do not fit what you're seeing, you have to reason to suspect a seizure disorder. A lot of us like a good mystery, trying to figure out the pieces, and trying to solve the whodunit. That's similar to what I'm going to walk you through. We're going to look at a lot of different pieces and as we prove and disprove those, we can assign them to those sides of the columns and help us clarify the picture of seizures. We need to ask questions and discard the reasons that don't fit, but keep the ones that do.

Some of the basic questions we need to ask ourselves is really looking at the environment for a child. Are they hungry? Did they take their medication that day? Is their medication wearing off? Did they sleep last night. Are they getting sick? All those environmental pieces. How do you even start to figure all that out? One of the simple data collection tools you can use is called a scatter plot.

Here’s a sample of a scatter plot. What it is it's just a chart broken down by days and times. When you observe the child and you see a behavior you think might be seizure-related, you just put an x in that time block. You continue to do this over a couple of weeks. Then after a couple of weeks, then you can look and say, "Okay, do we have a pattern? Is there anything that jumps out at me?"

Here’s a sample of some behavioral episodes. Do we see more behaviors in the morning or the afternoon? Are they happening more often before lunch? After lunch? Medication is being given at 11:00 every day. Is it happening around that time? Is it more toward the beginning of the week? The end of the week? Just
looking at something like this is going to help you to weed out, "Oh, you know what? They're having that behavior every day 20 minutes before snack time." That may be they're hungry. It's going to help us to more refine what we're looking at.

Now that you've been able to eliminate a few of your causes through the scatter plot, we're going to go back to those functions of behavior. You need to move on to take a look at what's called an "Antecedent Behavior Consequence" data tool. Really all this does is you're looking at what happens before, after, and during a behavior. It helps us to link the reasons and causes for a behavior.

An example might be if the teacher says it's time for math, which would be your antecedent, the child starts to scream, and yell, and tantrum, that's your behavior, and the teacher responds with okay, we'll do math later, that's the consequence. Looking at that you can see a clear chain of events, what happened before, teacher says it's math time, child has a tantrum, teacher takes the activity away. What that actually is, to go even further, would be those functions that I mentioned, would be escape. It's the child's way of avoiding having to do their math activity.

Here's just a sample of an ABC, or an Antecedent Behavior Consequence, chart. Student is told to go to lunch, they flop on the floor, and they don't go to the lunchroom. A student is asked to put a preferred toy away, they throw the toy and start to yell, and the teacher takes the toy away. Teacher says it's time for snack, the student goes and gets their snack, goes to their desk and has their snack. In all three of those examples, you can see how those events connect. With behaviors that are seizure related, you won't find those connections. You won't be able to nicely line them up. If you have behaviors that you can't line up with an antecedent, the behavior, and the consequence, again, this is giving you more information that there may be some seizures going on.

This is just a blank ABC data sheet. There's many generic ones available on the Internet. The ones that Caren and I are using
will be available on our website in the next few weeks. I'll give you that address at the end of the presentation that you'll be able to download and use.

We now have some solid data. We have to start looking, is there a connection? There's a two-step process using your information. What you look at is the behaviors that were present with a cause. One of the things I suggest that you start out with is looking at the child's cognitive skills, self-stimulatory behaviors, aggression, and communication. This is where you basically collect information on what is their cognitive skills? They are able to say what happened during an event. They can follow two-step directions. They can understand when they're angry, but not hurt people. Self-stimulatory, jumping up and down. This really is going to break down what it looks like in a typical behavior that you know connects to a function. What does their aggression look like? Do they punch, do they hit, do they scream? It's really important to have this as almost kind of your baseline information to make comparisons to.

As you're collecting your ABC data, what you'll start to see is you'll have behaviors that are presenting without cause. You've been able to eliminate the episodes that occur because of environmental factors, functions, the reasons behind them, and then what are typical responses. You're then going to be left with this core of behaviors that don't make any sense. What I suggest is you start to compile them by date, location, time, all those defining factors that are going to help a doctor to take a better look at your child.

The first example is in November of 2011, student was unable to be redirected from going after staff. Did not remember the incident when it was done. Their eyes had kind of a different look to them. They went to sleep after the event. These are the things that we saw that were not along the norms of what we said is behaviors that are present with cause, or the behaviors that we described as more of a baseline of where our child typically was.

As you look, you'll see each of the examples, there are more and
more behaviors that we became aware of. By February, we were noticing things such as his eyes were shifting to the left and quickly rapidly blinking with a fixed gaze. We tried to ask him questions, he didn't answer us. We noticed his mouth was starting to twitch, but he continued to stare. All these things were things we hadn't seen in his typical behaviors, but we couldn't connect them to any of the functions, or anything in the environment either. Again, this gave us hard data.

Here's a continuing of that episode, behaviors that we're seeing. He was not able to follow directions. Was not able to go to the front door and get his coat. He didn't recognize me when I walked in the room. Then smaller staring spells occurred throughout the hour that was following. Last thing was some confusion. Again, now you've narrowed it down to this whole list that you can't explain away. There's no logical reason for what you've done.

This is just an additional list of some other behaviors that just were odd that we just started to generate a list of. Things like his leg twitching, his throat clearing, tapping his head and saying, "Ouch," peripheral staring spells. The interesting thing is if you take these odd behaviors and you lay them against that list that I mentioned earlier of seizure-related behaviors, they're identical. There's no disputing that this is not a seizure disorder.

One of the other tools that you can use that I was recently introduced to, is the Rancho Levels of Cognitive Functioning. Which were created at the Ranchos Los Amigos Medical Center in California. I've included the website. What they do is, it's a scale of 1 to 10 that describes level of cognitive functioning where 1, the person's not responding, they need complete support, they're not responding to heat, cold, pain. Just no stimulation is having an impact on them. As you head up to number 5, they're confused, and they're not agitated. If you get to 10, it's purposeful and appropriate. By using this scale, you can reference where your child is in these behavioral episodes. Are they slightly agitated, or are they not responding? Again, it's giving you just more information, more hard data. Doctors respond much more favorably when you have that data to hand to
them versus just saying, "This is what I think is going on." This scale is a wonderful tool. I encourage you to check out their website as they have a lot of information on looking at the levels of cognitive functioning and on just activity in the brain in general.

If we move along to analyze your data. Now you've got your scatter plot. You've got your ABC. You've got your baseline of what your child typically is like. You have this list of unexplained things. Do you see any more patterns? Can you explain anything away? By this point, you've explained everything you can away and you're left with this core, this core of seizure-like behaviors. What you need to do at that point is then follow your gut instinct. Because then you know something is not right, something is not staying the course, it's not making sense.

The hardest part about approaching the medical professionals, as I mentioned, is our family went through five different neurologists until we finally got a neurologist who was willing to listen to us. These are the suggestions that I make to really make sure that doctors are willing to listen. First, write up all your data, so the charts that are available on our website, and the ones that I've shown in this presentation, make copies of those. Document the time, the date, did someone get hurt. What were all those little odd behaviors because if you give it to them they've got it as a point of reference.

Two, if you can catch an episode on video, do it. Put it on a DVD and take it to the doctor. Even catching it on your iPhone and playing it back to the doctor, they were able to then look and they can say, "See, their eyes are rolling to the left. Look at their leg is twitching." It gives you more hardcore evidence to prove that something is going on.

Three, one thing that I think is really important is, what I have found is many doctors want to review the episode individually. They want to look at each episode as a separate event. What you really need to do is encourage them to review all these seizures and episodes that have been happening
longitudinally, kind of going over the span of time. Because when you start to compare those pieces to each other is when you really start to see these patterns emerge.

What if they say, "No?" The doctor says, "No, you're crazy. Mom, you're nuts. Dad, forget it. I'm not doing this." Find a new neurologist. We live in a society where we're afraid to break up with our hairdresser because we might offend them. You have to find a new neurologist. Many, many people who I have talked to and who I have worked with have said they have seen many, many doctors and have been turned away. Don't give up. You will find that doctor who is willing to listen to you. I promise you that you will.

Thank you for giving me the opportunity to share this information. You can check out our website. Caren and I have a website which is www.silentlyseizing.com. I've also included my email address if you want to contact me further with some questions. We also provide consultation for a nominal fee.

[inaudible 00:39:32] I'll turn it back over to you for questions.

Interviewer: Thank you so much, Patricia, that was really interesting. I've been hanging on your every word. Fascinating.

We've got some great questions here. I want to remind you, if you're dialing in, please, you can ask a question by just hitting *2. You can email your questions. You can give me your questions by dialing *2, thus raising your hand and I will call on you.

This is such a very complex issue, Patricia. The first question is a pretty long question. I'm going to read it slow.

Patricia: Okay.

Interviewer: This is from Linda in Pristina Kosovo. She says, "Hi, my
name is Linda. My son, Don, who is 16 has CDD form of autism. We live in Pristina Europe, however, he was diagnosed at Yale. Four years ago he started to have seizures caused by epilepsy. First year on medication he didn't have any seizures. After a year, he started to have seizures again. Then the doctor added the second medication. He would have some seizures from time to time, and mostly he would be sick with flu. Eight months ago his doctor changed the medication again from Lamictal to Topamax. About six months now, he didn't have any seizures. However, he's now having some kind of nervous breakdown, tantrums, violent behaviors, I don't know how to call it. From time to time, maybe once a week, for like 10 minutes. His face turns blue and he has uncontrolled behavior. My question is can this be silent seizures as I have never seen him like this before? Thank you. Linda.

Patricia: I'm not a doctor, but it certainly sounds like it's quite possible. One of the things that's really difficult is getting the medication cocktail just right for people who have the seizures. Very often they do have to switch from the different types of medications to really get the therapeutic coverage. One of the things that I notice in the question is the statement about being sick with the flu.

Interviewer: that's what caught my attention. Yes.

Patricia: Yes. Because what's really important is that any type of illness lowers your threshold for seizures. When someone has seizures and they become ill, it is much more likely those seizures will come out. That's one thing that kind of caught my attention, looking at that. What I would do, again, I'm a little concerned with the "his face is turning blue" because that certainly speaks to something neurological. I would, again, go back and look at just how I talked about breaking down those behaviors. The silent seizures that seem to be coming out now, really looking at is there a reason behind them? Is there something you can connect them to, and really looking at breaking down the behavior Are you seeing things like his eyes rolling? Are you seeing parts of his body twitching? Is he remembering after something that happened? Really, as I mentioned, seizures tend to be very patterned. Look for things within these episodes that are reflective of the seizures he had previously, and that will give you some good insight into whether or not they're reemerging. I would look at the illness
piece, and then looking for those patterns to see if they mimic
the previous seizures.

Interviewer: Great. It sounds like she could benefit a lot by getting
that chart of off your website and charting the days and times
and the strange behavior that he's exhibiting. Am I correct?

Patricia: Yes. That's absolutely. Do start trying to figure out do they
connect to anything, and start to make that list of behaviors
with cause and behaviors without cause. You should be able to
match up pretty easily which column they fall into. Based on the
history, because that's the other piece I mentioned, is really
taking it over time. My guess would be that yes, these are
probably another form of seizure. They can manifest in different
ways in different parts of the brain.

Minta: Yes. I'm getting a lot of questions of things like of that
nature. Michelle from Fresno asks, "Could spells of extreme
uncontrollable laughter be seizures?"

Patricia: There actually is a type of seizures called a gelastic seizure.
It's g-e-l-a-s-t-i-c. It is characterized by uncontrollable
laughing. It's actually a form of a seizure. Absolutely, and
that is something that I've seen in lots of children I've worked
with. People always say, "They're just processing something from
an hour ago." Not necessarily. That definitely is a type of
seizure.

Minta: Interesting. Here's another one with fevers and seizures. Gina
from Petersburg says, "I believe that my son has had blank
staring seizures when he has a real high fever. An MRT," which
I'm not sure what that is, "an MRT showed nothing serious and
the doctor said not to worry. This has only happened once that
I'm aware of. Is he correct. I'm wondering." Is it something she
should worry about?

Patricia: Again, I think it's that when there's illness that lowers the
seizures threshold. What I would suggest is, again, starting to
collect information on when it happens. It sounds like it's not
happening that frequently that she's aware of. There are
different types of seizures that only happen when you're
sleeping. they could be occurring, or they could be happening so
briefly that she's not seeing them. That's when you really have
to start to take that data. You can look for the more subtle
signs. Are they chewing on the inside of their lip? Are there
times when he's doing that? That can be a sign of a seizure,
chewing on the inside of your mouth. Is he clicking his tongue?
Are his eyes turned off to one direction? It's those little,
subtle, subtle things. You really have to be a detective because
they're not very obvious. You really have to watch for them.
This is where I'm saying use your data, follow your gut
instinct. Not all doctors are knowledgeable about these type of
seizures. I have been astounded at how many doctors I have
spoken to and the doctor that I worked for with my son that I've
educated on this that had no idea that these things even
existed.

Minta: Isn't that crazy when that happens?

Patricia: That's what it ends up being. This doctor could be a wonderful
doctor, but in his experience and background, "I don't think
it's anything important. It's nothing you need to worry about."
However, the vast majority of doctors have no idea about these
types of seizures and how they manifest. Often, when you try and
have the discussion, they will look at you like you are the
crazy parent. Bottom line is I had doctors come back to me and
say, "You know what? You taught me a thing or two." That's okay.
It's finding those doctors that are willing to have that
correspondence with you.

Minta: It's good that they acknowledged that. Many doctors will just
be very dismissive. I really like what you said about finding a
doctor who will work with you and respect you. That's so
important. We are really our children's own best experts. Their
doctors don't know us like we do. If you can't get a doctor to
listen to you

Patricia: The one neurologist that we ended up finally, who has really
helped us, she looked at us and said, "I don't understand the
autism piece. I get the seizure piece. I'm not 100 percent
buying what you're saying, but let me look at the information."
She came back a few weeks later and said, "I'm convinced." What
she ended up doing was actually, as I mentioned, the EEGs often
don't pick up anything.

Another piece that I would give parents, too, is make sure the
neurologist is reading the EEG. Often a tech will read it. If
there's no glaring errors, they won't notice. What the
neurologist noticed with ours is when she really took it apart, there was a very small section where my son's brain waves were slowing. That indicated the seizure. But, it was so subtle that the four people before who looked at it said it was normal. It wasn't until she really, as the doctor, went through and took it apart that she found that.

Minta: Wow. It sounds very important, though, you get an EEG and you have to take that back to your doctor and have them look at it. I have to interject here a little personal story. I'm going to get right back to the questions. My son, Kyle, who I talk about a lot, he used to have, they're less frequent now, but he used to have like these just blank stares, like he would just blank out. His eyes would glaze over. I was convinced that he was having silent seizures and took him for an EEG. I was told that was normal. That makes me just want to run back to that, this was five years ago, it makes me want to get that EEG and bring it to a neurologist and say, "Do you see anything here because the technician didn't." That is brilliant.

Maybe people in the audience who have had these EEGs that were told were normal might think about having a doctor read this EEG. It should be standard practice.

Patricia: It should be. Again, stepping off my soapbox for a minute. Really, doctors don't want to be told that they're wrong. It's tough to do, but if you can keep thick skin. If you're not going to advocate for your child, no one's going to.

Minta: You're so right.

Patricia: Eventually you will find somebody who sits down and says, "You know what? This is what I saw." Bottom line, once you have someone, one of the doctors that we worked with laid everything out. He said, "When you lay all of this out, there's no denying. This is a classic seizure disorder. I can't believe anybody missed it."

Minta: Unbelievable.

Patricia: It's getting those pieces. Bringing in those little pieces that you collect and eventually building a case. I feel like you're almost building a case like you're going to court. You're bringing all your documents, and all your evidence and now put
it together. That's what families are having to do and they're having a tremendous amount of success and kids are getting better.

Minta: That is just a tremendous piece that you bring to us. I've got more great questions I want to get back to. From Oklahoma City, "You are describing my son to a "t" right now. He just had an emergency EEG because the doctors and psychologists thought this new behaviors were actually seizures. The EEG said they were not seizures so we were back at square one. I don't know how many more times my heart can take him grabbing his head and crying, "What is wrong with me?" Sounds just like your son. "I wish it was the old days when I loved you." What can we do to get this deep EEG done?"

Patricia: That's where I would suggest if you can get the EEG and have another doctor, have another neurologist look at it. Get a second opinion looking at it. Again, we went through four doctors before we got someone who actually read it the way it was supposed to be read. Gosh, it's so hard.

Minta: I'm sorry to interrupt. What I'm hearing from this person in Oklahoma City is what the last thing they said, "What can we do to get this deep EEG done?" I get the feeling [inaudible 00:52:02]

Patricia: I'm sorry. [inaudible 00:52:02] part.

Dr. Miranda is out in California and the Bright Minds Institute. You can contact him through his website and they can give you more information as to how to do that. At this point, he's the only one who has this and is specializing in it. That would be my best advice to get that done. Again, I would continue to collect the information like I've talked about because, again, it's not feasible for everybody to fly to California and have that done. Hopefully that technology will eventually spread where it's available to all kids who are diagnosed with autism. I would contact the Bright Minds Institute.

Minta: Great advice. Let's hope that you will bring more awareness to this. Oklahoma City, don't give up on the deep EEG, and hang in there. It will get better.

Yes, thank you.
Kristin from San Clemente has a very good question. "Can low blood sugar be a trigger for seizures? My ASD son seems to have explosive behaviors when he is hungry. He is irrational, irritable, and often aggressive during those outbursts. They can last 5 to 30 plus minutes. After he eats and calms down, he's a different person, apologetic, etc." Can low blood sugar be a trigger for seizures?

Patricia: Not necessarily a trigger for seizures, but it can definitely set off a chain of behaviors. Prior to us going into figuring out my son had seizures, we investigated the blood sugar piece. That was something we did look into. If their blood pressure crashes because of low sugar, and they haven't eaten, absolutely, you can see a manifestation of similar behaviors. What it comes down to is, again, looking at the list of behaviors that tend to more seizure-based. Are you seeing the eye rolling? Are you seeing the chattering of teeth? Are you seeing twitching of body parts? What is their memory after? That's also a really important piece. Are they remembering what happened? Or, are they completely confused and disoriented? You really have to look at what they call the "postictal" state which is right after the seizure. Looking at are they confused, are they tired, are they disoriented because that's almost just as important as the behaviors you see during the episode. That will also let you know if the behaviors are they really behavior with a reason, as I said, or are they the seizure behaviors. You will have a postictal state if it's a seizure.

Minta: She said he gets apologetic. Kristin, my advice is give him frequent snacks for now and maybe get a test for blood sugar, see if he might have some hypoglycemia.

Patricia: You can do that. You can break it down where he's getting six meals so that blood sugar stays stable and collect the data as I suggested. Listing those behaviors. Do your ABC analysis. Was there a reason? Was there a cause? Does it stabilize out? You can also use the scatter plot and mark in exactly where the child's eating. Then put x's in and you should be able to see a pattern emerge if when it's happening in relation to when they're eating. That will also help you very easily tease that piece out.

Minta: Good advice. It seems like anybody out there, who if you
suspect your child might have a seizure disorder, then these charts might really be very helpful to you. I'm going to start one myself tonight I think.

I want to remind the audience again, I don't see any hands raised. If you're dialing in, this would be such a great opportunity for you to ask Patricia a question if you even suspect that your child may have a seizure disorder. Please call in, dial *2 to raise your hand, speak to Patricia directly. I'm going to now take one more question for now. I really want to encourage you guys to call in.

I think we've answered all of the questions. I think that we've answered all of the questions that I have coming in. While I'm waiting for another question to come in, let me ask you. There was one question from Monica from Houston again. She wants to know how seizures affect personable autism. Let me read you her whole question. My son is low functioning personable autism. He's 17 years old. He has started having seizures, tonic-clonic seizures, for the last year. Will he ever come out of them? How do seizures affect a person with autism?

Patricia: Starting with how they affect them. One of the biggest things that you often see is a regression in skills because the bottom line is when you have a seizure, it's a brain injury. It's an injury to your brain. We also have to kind of look at it in that respect as well, is that each time our kids seize, the brain is being injured. A lot of times you'll see a regression in their language skills. My son went from speaking in seven- and eight-word phrases and chunks down to one word at a time. We were getting one word responses. They were not very clear. The skills that they may have in terms of their life skills, being able to read a simple book, or to make a recipe, or fold laundry, things like that, you'll see a reduced ability to do that independently. Almost like they've forgotten that skill. If you have a child who you can say, "Go get your coat at the front door, and your backpack, and meet me at the car," and now they're walking to the door to get their coat and they're just standing there staring at the ceiling because they have no idea what you've said. You see regression in those skills.

You also may see a reduced tolerance for things. That
frustration tolerance may be very, very low. It doesn't take much to upset the apple cart, so to speak. When you see those kinds of things. Some other things that you also can see that may not necessarily be the personal, with autism is, there are some physical symptoms that you may see. There can be a change in the person's skin tone. There have been children, and I know my son was one, where he would turn almost a yellowish color. There was almost a yellowish, like jaundice cast to his skin in the weeks leading up to having a seizure. So things like that, but the big thing is you see a regression in the skills that they had. Things just start to disappear. As I mentioned in the one slide, things to flow away from them. You start to see all these things that they had, all these great skills and abilities are gone. It's like, "Wait a minute. You know how to do x, y, and z. How come you can't remember how to brush your teeth? Or you can't remember how to find your locker? You knew how to do this." That's the big thing that you'll see in people with autism. Again, the seizures cause those behaviors. You may start to see a huge increase in challenging behaviors that you didn't see before. Again, that's where the charts and graphs and everything are really, really important.

A lot of times what I find, too, especially with the teen years, is people will blame the behaviors on hormones. "They're in puberty. That's what happens when kids with autism go through puberty." Again, it's looking at what is typical for your child, and what is different now. That's really the best way to measure it in people with autism.

The rest of the question, in terms of will they ever come out of them, it's really hard to say. The brain is amazing in the way it can heal itself, and the things that it can do. In some cases children are on seizure medication their whole lives. Sometimes they're able to stay on the same dose, same cocktail, same brand. Other people are having to change every six months. It's kind of an ongoing battle. I don't think you can ever be complacent and think they're gone because I have found that when you are like, "Yeah, they're gone," all the sudden one pops up and you're like, "Oh, we're back to square one." Don't think they ever completely disappear, but the regression is definitely how it impacts our kids the most.
Minta: That is such a helpful tip. We really do have to be so observant of our children. It's easy in the day to day to lose that. That chart sounds like such a great idea.

We have some callers on the line now. I would like to speak to Wallia [ph] [inaudible 01:01:38] from Houston, Texas. Wallia, are you on the line with me? Hold on. Oops, sorry. Wallia can you hear us?

Wallia: Yes.

Minta: Hi, Wallia. Welcome to the show. Do you have a question for Patricia?

Wallia: Yes, actually you were giving the answer to my question regarding my son who is having seizures, and yes, you gave me the right answer because that you're talking about regression. His personality totally changed after starting having seizures. He has so much of the sensory needs now. His frustration level is very high right now. He gets into the anger mode, and he starts shaking and all that. Right now, he didn't have any seizures since November the 9th. We added the sleep medicine to it because he was on Risperdal first and then we took him off to put him on Abilify. The doctors told us because we took him off the Risperdal that's why he's not sleeping well and that's why he was having every 15 days. Every three weeks we kept increasing the trial dose and it didn't help him. Then we put him on Trazodone for the sleep. Since then, so far [inaudible 01:03:11] , he didn't have any one. Definitely, we are experiencing a lot of sensory needs right now. It's like he's totally changed personality. Is there anything you can help me with?

Patricia: No. Typically then once the seizures are under control and everything has stabilized, often you'll start to see those things start to fade away. You'll get more of your typical child that you knew back. I have found when you're in it, the flux of changing medications, and there's a lot of changes going on, that is often when . . . Your children, they're unstable, too. You'll see things that are just not out of the norm for them. It takes time for the medications to stabilize, for their brain and their body to stabilize because these are serious injuries to their bodies. It really disrupts everything about you, your sensory, your systems, all of those things.
Wallia: He has lost a lot of weight, also.

Patricia: I'm sorry?

Wallia: He has lost a lot of weight, also. He was already a thin, lean boy and now you can see. Everybody is asking me, "Is he okay?" Like that much weight he has lost.

Patricia: I would question, too, with that is you said that he went off Risperdal?

Wallia: Yes. Last summer we took him off from the Risperdal and he was put onto the Abilify.

Patricia: I known with Risperdal, one of the huge concerns when children are put on Risperdal is it causes them to gain a tremendous amount of weight.

Wallia: He didn't.

Patricia: When you take them off, even if they didn't gain a lot, a lot of times when they take it off, then they start to drop a lot of weight. It's kind of your body, again, that's restabilizing.

Wallia: Do you know how much time it's going to take, because he is underweight right now? He's 5'11' and he's 114 or 115 pounds.

Patricia: Okay. Is he a picky eater?

Wallia: No. He's a very good eater.

Patricia: He's a good eater.

Wallia: He is a healthy eater. He's a soup, salad person.

Patricia: I always use as kind of a time frame, and again, I'm not a doctor, but you need to give the body a good six months to really stabilize from a medication change.

Wallia: And the seizure free, right?

Patricia: Yes. Really getting that body back to stable. That can take six months. Sometimes it's longer, sometimes it's less, but the body has to go back to finding its balance.
Wallia: But in the meantime, in the school or so, can you give us any advice? We went back, too, because teachers weren't able to control him, so we were having a lot of troubles. We kind of come back with the remedy was let's just shorten his days. We started picking him up an hour early. Because you have a teaching background, I just wanted to ask you because before I have been hearing all those webinars. I found your one is the best one, very interesting, and the slides and all structured very beautifully. Yes, you can see you are a teacher who has art as a background. I can see that. I really appreciate your webinar.

Patricia: Thank you. We went through the same thing with my son where we ended up, I took a leave of absence from work. He only went to school three days a week. Then, for a while, he was only going half days. Really that was when we were really trying to stabilize the medication, because he was so dangerous. He dislocated the shoulder of one of the staff in the room. He bit the principal. He was so dangerous. What school was telling us was, "We're just going to restrain him and hold him to the ground when this happens," which you can't for a medical condition. That's not what you do.

Wallia: Yes. That's the problem with my son. As you said, the restraints. He can't handle the restraints either. He becomes very furious. He gets those anger things inside, like that rage comes out of him. Then I have to keep him home for a week to calm down his rage. To calm down his rage, I have to bring out the strength from my [inaudible 01:07:36] inside, like emotional strength to keep him calm.

Patricia: That, again, would say that his medication is not stabilized. I would question if you're still seeing those rages, then either the dosage is not right, or he's not on the right medication. Or, they have changed too many things, too many medications. Going off the Risperdal, adding the Abilify. There seems to be there's at least four different medications you mentioned that have been changed or altered. That can also complicate things. Doctors should only change one thing at a time and give it some time. It's also kind of hard to look and say, "Okay. Is it that he is on the Abilify? Is it the Trileptal went up?" It's hard to break those pieces down. It seems like a lot of changes were made in a short period of time. Again, it doesn't take much.
When you’re on different medications, different medications can lower that threshold, and make seizures more common. You might need to step back and really take a look at the medications. Really advocate for only changing one at a time.

The teacher in me . . . Safety is a priority. What we did is I've helped kids in schools, the teachers create safety plans so when the child starts to do something, or starts to get upset, they have almost like a fire drill, an evacuation procedure to get the other kids out of the room so that everybody knows what to do, and everybody knew who to call, and the teachers and the principals in the building all had walkie-talkies that they would call so extra people could come help. We really created like a fire-drill plan. [inaudible 01:09:31]

Wallia: Yes. I think that's exactly what we are working on right now, because he has already [inaudible 01:09:36] that behavior continuum for him and that is 20 pages long. It says everything, when he does this, do this and all that. I'm just like turned off because keep telling them what to do, and still not following through, so this is what we came up with. We are going to present that to them so that they should follow that.

Patricia: Here's my other question, which is probably a little bit off-topic, does he have a behavior consultant? Somebody who he can go in and do that for you because it might carry more weight [inaudible 01:10:11].

Wallia: The AB person? No, no. But I do have an in-home trainer who has the training in that AB and stuff. Myself went through and that's what we are working together to see. That's how we are working.

Patricia: Great. That sounds like a great plan because you are being proactive.

Minta: I'm sorry to interrupt, but in the interest of time, I'm going to ask you guys to just say a few more closing words to each other. We have a lot of callers calling in.

Wallia: Okay. Thanks very much.

Patricia: Okay.
Minta: Do you have any other questions, Wallia?

Wallia: No, no. That's it.

Minta: Thank you so much for calling in. You brought up such wonderful points. Thank you so much for calling in and sharing your story with us.

Okay. Are you still there with me?

Patricia: I'm here.

Minta: Patricia, you're here? Okay. She hung up. Very good.

Patricia: I'm here.

Minta: Okay. We have another caller waiting on the line. Nathan Aaron from de Mona. Nathan, can you hear me? Hold on. Nathan, are you on the line with us?

Nathan: Yes, can you hear me?

Minta: Hi. Yes, I can hear you Nathan. Hi, thank you for calling in. Hi. Do you have a question for Patricia?

Nathan: Yes. I would like to know how long do laughing spells have to continue for it to be considered a gelastic seizure, a possibility of it being a gelastic seizure?

Patricia: They can be very short, from 5 to 10 seconds, or they can be an uncontrollable laughing fit that's 15 minutes long. There's really no specific time that qualifies it. It's more just the evidence of it happening. Again, it's going through and figuring out that it's not related to anything.

Nathan: Does it always have to have a sardonic nature? Can it seem like regular laughter? I don't know how to say it. Just regular laughter in terms of being happy, as opposed to someone laughing but them looking like they're visibly not enjoying it?

Patricia: I think it comes down to really knowing what those typical characteristics are. How does the child behave when you know it's something that's happiness? I would pay real close attention to how it sounds, what their facial expression looks
like, what their body is doing. When you know it's more they're happy because they've got their favorite show, or they're doing something outside they enjoy versus those episodes. See if you can compare. Do they have the same look on their face? Looking for those subtle symptoms. Again, those subtle things with different body parts moving, twitching, things like that that will give you more information. It's really about observing and knowing what's typical in the child and then what doesn't fit into the realm of what's typical for them.

Nathan: Okay. Thank you very much. As it happened, somebody called in right as you began to answer, but I think I got most of what you said.

Patricia: Oh, okay.

Nathan: All right. Thank you.

Patricia: Sure.

Minta: Thank you so much for calling. Thank you. Okay. We're going to go back to our email questions. Patricia, you are so on. Thank you so much for being so helpful to my callers.

From Jennifer from Wadsburg, Ohio. I've got some questions that are a little complicated here, and very fascinating. Jennifer from Ohio says, "My son will frequently wake up in the middle of the night, start screaming and biting his arm. He will also sometimes have episodes like this during the day that seems to come out of nowhere. When I try to talk to him during these episodes he does frequently respond to me by looking at me. He's non-verbal. Could this still be a seizure? He also frequently seems to have headaches and I am wondering if this could be related as well. These episodes often increase when we have a storm system moving through. I am wondering if weather shifts can be triggers for seizures?"

Patricia: It could be a seizure. The other thing I would question are migraines. That was something else that we looked into as well because often our kids can have migraines. If you talk to anybody who works in education, they will tell you that when barometric pressure changes, kids have behavior. It's without fail. That, and the phases of the moon. It really does disrupt their systems. Seizures, again, can frequently happen at night
when we're not aware of them, so I would definitely be concerned about the waking up, the screaming, and the biting. Again, you're going to have to tease out what could be nightmare versus what could be seizure. If it's also happening during the day, again, that's when you're going to look at those behaviors. Some of the more simple seizures that can happen, the child will turn and attend to you. They may be able to turn and attend to you and look in your direction. But, that doesn't mean a seizures is not still happening in their head.

Yes, the weather can affect it. Yes, they do happen a lot at night. With some seizures they can attend and look at you.

Minta: I never knew that. Thank you. I have another question here from another Jennifer from Orlando. Jennifer from Orlando wants to know, "My son is 17 and you have described what I have seen for him for many years. I have asked doctors about his behavior being related to seizures and was told no over and over. He would have episodes where suddenly without cause he was literally jumping off tops of furniture, or hurt his sister by jumping up and down on her. Immediately after the episodes he would be lethargic and did not know what had happened. He did have EEGs and all indicated abnormal findings, yet none would diagnose with seizures. He has never had a normal EEG. Currently he has similar behaviors, yet not as intense and not near as frequent. When these episodes slowed, he improved on all developmental levels."

Patricia: That would, to me, [inaudible 01:17:14].

Minta: It's a long question. Can you address that first, then we'll get to the second half?

Patricia: Yes. It definitely sounds descriptive of what the silent seizures would be like, especially when you're seeing that there's cognitive loss when the behaviors are more frequent, and then the episodes have eased up there's been cognitive growth. It definitely sounds like that there are the seizures are happening. They do tend to wax and wane. You may have a whole lot of them for a couple weeks, and then you may not have any for a couple months. What she's describing pattern-wise definitely fits a seizure disorder of the silent seizures.

Minta: Okay. The second part of her question is, "I already have tons
of documented data which I have presented many times to doctors, and while his episodes are not as frequent, they still continue. Do you have suggestions on how to get a doctor to listen even when you have provided written data and have recorded numerous EEGs which have been presented to doctors which show abnormalities but no active seizures during EEGs?"

Patricia: One of the other things I haven't mentioned that sometimes you can actually ask a doctor to, if you can get one to work with you to say, "Okay. I know you're saying you don't believe me." But some doctors will actually do a trial of anti-seizure medication. If you can ask them to do that, sometimes they'll do a trial run with you. You would continue to take the data to see if you're seeing changes. Sometimes they'll take that as the evidence that the medication seemed to improve the symptoms. It's a long shot, but I have had families who have ultimately, after going to doctor to doctor, have been able to do that, do a trial of an anticonvulsant, the child improves on the anticonvulsant and the parents are able to use that as the strong arm to say something is going on.

Minta: Good advice. Mary from Happy Valley Goose Bay asks, "My son was diagnosed epileptic when he was three. He was having four different types of seizures. When we thought he wasn't seizing, he was carrying on conversations with the technologist, playing with toys, etc., his EEG showed constant seizure activity. This was when he was three. Epilepsy runs in our family. He was able to stop his medication when he was seven and his EEG is now clear. He has never had violent tendencies, but he does laugh uncontrollably, sometimes, and forgets things very easily. Has language delays with comprehension and stuff. He was diagnosed with PDD at age nine. It seemed to be an increasing issue, not getting any better. Should we go back to his neurologist to discuss the possibility that his seizures have either returned or continued and are causing brain trauma?"

Patricia: Absolutely. I would go back to the neurologist. As I mentioned, this is a brain injury. It's impacting their brain, so if he's continuing to have them, it's causing injury to his brain. That has to be established. Especially with an accurate diagnosis of epilepsy already and family history, I would make the call Monday morning to absolutely get him back in and get him evaluated as soon as possible because it's very, very possible that they . . . Silent seizures, they fly under the radar.
Absolutely.

Minta: Yes. That's the whole point. It must be so frustrating to these parents, as it was for you, when you're not being listened to.

I want to remind the callers again please, we have such a fantastic expert here with us. If you have any questions regarding seizures or autism, please, if you're dialing in press *2, raise your hand and you can speak to Patricia yourself. I don't see any other questions so I may ask you one right now [inaudible 01:2145] myself. I don't have the incoming questions, so let me ask you one while I'm waiting. Please submit your questions. You have been answering the questions so right on. I'm so happy to hear this.

If you happen to suspect your child has a seizure disorder, you may have already answered this, since autism can look so much like seizures, if you see there's a problem with your child and you see symptoms that could be very confusing, where would a parent start? Would they start with a developmental pediatrician, a neurologist? Where do you think, if you see your child exhibiting some behavior that you just don't understand, what would be a good place to start for a parent?

Patricia: I think if you have a doctor of some type that you are working with that you have a good relationship with, you can start with them. We started with our pediatrician, just our everyday pediatrician. From there, we went to a psychiatrist who was prescribing my son's behavior medication and said, "What do you think?" We started as simple as that because to find somebody who is such an expert, even to get in with a neurologist, you're looking at months, and months, and months of waiting. Start with the doctor that you use for everything. Even if they tell you, "I don't know," ask them to call a colleague. "Can you call someone?" We asked our pediatrician and he said, "I have no idea, but let me call a friend of mine who's a neurologist and see what he says." Even starting that simple it's enough to get the ball rolling. You can start to get the professionals involved and then work your way through. Then maybe you can get in and talk to that neurologist, or maybe that developmental pediatrician.
Sometimes, too, different programs in schools have people that will come in. I know some of the programs here in New York where I am, have developmental pediatricians and psychiatrists who schools contract with to come in and actually do this kind of consultation with families.

Ask other families. Get creative with who you can talk to. Even just starting with your pediatrician, your family doctor who you see, and say, "Okay, you don't know. Tell me who to go to next." Start with that person that you trust and move from there.

Minta: Good advice. Now here's a practical question that I'll throw out. Let's say that you've been advised to give your child a seizure medication. But your child, he may be autistic and have these seizures, he may have sensory issues, how would you get a child who doesn't swallow a pill to take his medication?

Patricia: There are many, many ways. This is a good person to talk to, and I'll give some suggestions, but a good person to talk to is the speech therapist, a speech pathologist, because they can often help you with swallowing programs and feeding programs. Actually, I know that there are some agencies and programs that have pill swallowing programs that can teach them. Certainly you can get the medications in a liquid form, which kids don't like. You mix it with apple sauce and this and that, and everything else.

Minta: Then they don't eat it and then you [inaudible 01:25:43].

Patricia: They don't eat it and you've wasted all this money on this special yogurt that you thought they'd like. I know many pharmacies do have flavor additives that they can add to the medications.

If you're looking at pills, the problem is many of the seizures pills that I have had to use with my son are huge. They're the horse pills. Get a pill splitter and break it into four pieces. If you break it into four pieces, it's the size of half a Tic-Tac. You can put that in applesauce or something. Then it's smaller, it's not as obvious. It takes a lot of practice. What you can even do is just practice with just taking the spoonful of applesauce from you, or of yogurt, or ice cream, or whatever so there's not always medication in it.
I have always found it helps to be honest. I don't like to sneak it past them, because I think that sets up some trust issues.

Minta: Absolutely. You can't sneak it past them either. They're much smarter than that.

Patricia: They're incredibly smart.

Minta: [inaudible 01:26:51].

Patricia: Yes, they know. Often what I'll do is, you can find pictures right on Google, of take your medicine and then you get whatever, that basic contingency for behavior. But tell them, "You're going to take your medicine. It's going to make your head feel better." Be honest with them. Have that conversation with them.

Minta: You could use a social story.

Patricia: A social story, absolutely, that this is what you need to do because maybe they can't verbally tell you, but I guarantee you, receptively, they know exactly what's going on. Use a social story. Use a visual strip. Practice, practice, practice, and reinforce.

You can also purchase, a lot of times if you talk, there are different companies, or if you talk to the pharmacy, you can get empty capsules to practice with so there's no medication in them. If you try that then they're still getting the experience and the practice, but there's no medication in them to harm them. That's something else you could do.

Minta: What great suggestions. We are almost out of time so I'm going to ask you if you would like to wrap up. What else would you like to say to our audience. We've got just about one minute left. Can you just give us a brief summary and any information you'd like to share?

Patricia: I just believe that if you feel that your child is having seizures gather the information and be prepared to fight. You may have to go to a dozen doctors, but I guarantee you, when the brain starts to heal, now that I'm at the opposite end of going through this, and we still have to watch my son and every so
often a seizures pops out, but the quality of life that your
child will have, and on those days when you're frustrated, and
you're angry, and you just can't move on, remember it's about
making the quality of their life better. It is so, so worth it
in the end. You will find someone who will listen. It make take
a while, but you will find someone.

Minta: Thank you so much for all your great advice and encouraging
words, Patricia. Thank you so much for being with us tonight.
Thanks for helping so helpful to our audience. I hope [inaudible

Patricia: It's been a pleasure.

Minta: Thank you so much. Have a great evening. Good night, viewers.
Good night. I'll meet you in half an hour. Thank you. Bye.